

Congresswoman Cathy McMorris Rodgers
Opening Statement
Affiliates in Action Forum on Persons with Down Syndrome
February 26, 2009

Thank you to each and every one of you for being here and for your commitment to building purposeful and happy individuals, families and communities. I appreciate your knowledge on issues that concern individuals with Down syndrome and their families across their life span.

As you may know, my wonderful 22-month-old son, Cole, has Down syndrome. I understand first-hand how difficult it is for new and expecting parents to receive the news that their new baby or their unborn child will have a disability. Every parent has hopes and dreams for their child, and Down syndrome is not on that list.

While great advances have been made in the medical research and public policy arenas to enhance the lives of individuals with Down syndrome, there is much more that can be done to meet the needs of the Down syndrome community. We must improve the quality of life of individuals with Down syndrome by raising expectations and improving outcomes in education. By eliminating barriers to economic opportunity in employment, promoting programs that encourage savings and investment and by increasing funding for research that accelerates the development of effective treatments and therapies.

Access to a top-notch education should be available to all citizens in this country including those with Down syndrome. As a member of the House

Education and Labor Committee, I am eager to hear from Chairman Miller on what the Committee's priorities will look like this year. No Child Left Behind must be reauthorized and I believe this is a real opportunity to improve special education in our country to ensure that every child lives up to his or her full potential.

As you know, the life span of individuals with Down syndrome has increased over the last few decades. This is a concern for parents because children with disabilities can not have any real assets if they would ever need to apply for federal benefits such as Medicaid and they can't use typical tax-deferred savings plans because they may not go to college or become financially independent. I believe we must allow parents to save for their child's future and give them an added layer of security to help individuals with disabilities live full and productive lives. Financial Savings Accounts could provide flexibility, portability and financial security to families. I look forward to working with my colleagues in the House and the Senate on legislation to create this type of savings account.

When the Caucus launched last May, we heard from the National Institutes of Health on its plan to advance the understanding of Down syndrome and to speed up the development of new treatments for the condition and associated medical problems. This news gives us all hope.

However, as many of us are aware, the National Institutes of Health funding for Down syndrome research is disproportionately low relative to the potential for translating and developing effective new treatments, and broadening our understanding of secondary disorders. NIH funding for

Down syndrome decreased 43.5 percent from 2003-2008. We must do everything in our power to reverse this trend and this effort begins with our efforts here today.

In addition, it is deeply troubling that 80-90 percent of patients who are told that the child they are carrying has Down syndrome choose to terminate their pregnancy and the percentage is similarly high for children with other prenatal diagnosable conditions. It is my belief that one of the main reasons for these high figures is that many people in society still believe the outdated stereotypes and misconceptions that continue to exist about people with disabilities.

I believe the Prenatally and Postnatally Diagnosed Conditions Awareness Act or commonly referred to as the Brownback-Kennedy bill is a positive step forward in helping new and expecting parents of children with special needs get accurate information on the real potential of their children. This sort of information is critical at the time of diagnosis. Today, because of the advances in technology, we offer diagnosis for Down syndrome prenatally and soon we will be able to diagnose other genetic disorders and diseases prenatally. Down syndrome has really been on the forefront of what new technology, beyond ultrasounds, can diagnose like genetic disorders and other abnormalities. This new technology raises a lot of other questions. What are we going to do with this information?

I cannot overemphasize how important this is. As many in this room know, the news that your child may have a disability is shocking. The fear of the unknown can be overwhelming and we need to ensure that parents are not

only told about the risks, but are also give information about the rewards and love that these children bring into parents lives each and every day.

It is a top priority of mine to work with the House Appropriations Committee to ensure this program will be funded adequately so that this information is available to make sure that parents along with the diagnosis are given accurate and up-to-date information as to the potential, resources, and support that exists. It is so important for them to know that they are not alone and that others have struggled with their questions and answers are available.

Because of my personal experiences with my son Cole, I have made it my personal goal to increase awareness of the capabilities, value, and worth of people with disabilities. I am committed to helping families and individuals with disabilities have an opportunity to lead full, happy and productive lives.

I look forward to hearing the thoughts and perspectives of our “witnesses” regarding these priorities so children and adults with Down syndrome will continue to have a special and positive impact on this world.

Thank you.